

DUCHENNE MUSCULAR DYSTROPHY

Taking charge and letting go: exploring the ways a Transition to Adulthood project for teenagers with Duchenne muscular dystrophy has supported parents to prepare for the future

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The new Special Educational Needs and Disability legislation in the Children and Families Act 2014 intends to raise the aspirations of young people with special educational needs and their families, and improve their life outcomes. But what do raised aspirations and better outcomes look like for young people who have a life-limiting impairment? This article draws on data from a parent evaluation of a lottery-funded Transition to Adulthood project for boys with Duchenne muscular dystrophy (DMD), called 'Takin' Charge', focusing in particular on whether or not the project helped parents of boys with DMD prepare for the future. Key themes that emerged were the importance and novelty of older role models with DMD in the project who were able to share their journeys into adulthood, the support between families that the project enabled, the meaning of family resilience and aspirations for a normal life. The use of solution-focused questioning with families affected by a life-limiting impairment is also explored.

Key words: Duchenne muscular dystrophy, life-limiting impairment, Children and Families Act 2014, resilience, aspirations

Duchenne muscular dystrophy (DMD) is a genetic muscle wasting impairment that affects around one in 3,500 male births (Emery & Muntoni, 2003). On average, young people with DMD become wheelchair users by the age of 12 years, and without treatment the mean age of death is 19 years (Bushby et al., 2010). However, interventions such as ventilation and cardiac care over the past 20 years have increased life expectancy, and mean age of death was reported as 27 years in 2007 (Eagle et al., 2007). The landscape for DMD has therefore changed considerably, but evidence suggests that society has not kept in step with these medical improvements, and often young people and families are still not encouraged to be aspirational about the future (Schrans et al., 2013; Abbott et al., 2012).

The experience of transition to adulthood for teenagers with DMD

The term 'transition to adulthood' refers to the process through which young people with special educational needs and disability start to prepare for their life after school. In education, this process has traditionally begun at the age of 14 years, and post-school options have been discussed in annual Statement review meetings from Year 9 onwards. In the health and social care sectors, transition is referred to as the time when young people begin to think about moving from paediatric to adult services, which happens around the age of 18 years. The experience of transition to adulthood (transition) for adults with DMD in the UK has not been a positive one. Abbott et al. (2012) report, from interviews with 40 men with DMD and their families, a lack of expectations and little or no planning as they grew up because no one expected them to be alive. As a result, services had to be fought for, which was stressful and confusing for both young people and their parents. Out of the 40 men that were interviewed, only one was in paid employment, with a third not in employment or training for up to seven years. All lived at home with parents and had a limited social life. Eighty percent of parents had reached a clinically depressed stage. Similarly, in research with adults with DMD in Denmark, Jeppesen et al. (2003) report that only one adult had paid employment, and urge parents and professionals to 'anticipate that the DMD boy grows up into manhood'. In a study of 28 young adults with life-limiting impairments, eight of whom were young people with DMD, Beresford and Stuttard (2014) report high levels of anxiety as young people transition from paediatric to adult health care, and suggest that young adults going through transition have a worse experience of health care than either those who are younger, or

older adults. In other studies, adults with DMD are described as unanticipated and marginalised (Gibson et al., 2007; Rahbek et al., 2005; Schrans et al., 2013).

Transition for young people with special educational needs and disability

These findings reflect the experience of young people with special educational needs and disability in the UK in general, whose provision through transition has been found to be inadequate, with a lack of emphasis on life outcomes and achievement, inconsistent providers and a lack of joined-up thinking, with families and professionals both unsure about the system (Ofsted, 2010; CQC, 2014).

The Children and Families Act 2014 aimed to address these issues, and has been viewed as the biggest shake-up in special education for 30 years (Tutt & Williams, 2015). The Act is intended to raise aspirations, placing the young person and family 'at the heart of the process' (DfE & DoH, 2015), with an emphasis on co-produced outcomes rather than provision.

Although it is too early to assess its long-term impact, recent evaluations of the new legislation indicate a positive response from young people and families, with the evaluation of the Pathfinders Pilot Programme showing overall high satisfaction with the changes, and a more recent small-scale project reporting that young people and families prefer the new person-centred philosophy (DfE, 2014, 2015, 2016).

What was the Takin' Charge Transition to Adulthood project?

Takin' Charge was Action Duchenne's lottery-funded transition project which ran from 2011 to 2016. Its agreed objectives were to support teenagers with DMD to be better able to make career and life choices, be less socially isolated, be more confident and be able to advocate for themselves in relation to their medical, social and sexual needs. All of these issues were addressed through workshops with the support of both adults with DMD and specialist providers, and were organised to reflect the four areas of the special educational needs and disability outcomes: employment; independence; health; and lastly social inclusion. Workshops were either run as part of Action Duchenne's international and national conferences or in partnership with local hospices across the UK. The project also worked with parents through 'Letting Go' meetings, where information, strategies and support systems could be shared, and with siblings through 'What about us?' sessions where siblings could reflect on their own needs and enjoy a fun activity workshop. Finally, a small group of adults with DMD were recruited as part of a steering committee to support and determine the direction of the project.

The role of transition programmes in DMD

The focus of employment and independent living throughout the transition process in DMD has been questioned by some, who suggest it plays a ‘normalising’ role, and that for those living with DMD there may be other things in life that are more important than the trajectory of school – college – work (Gibson et al., 2014; Hamdani et al., 2015). From interviews with 10 adults with DMD in Canada, Gibson suggests that they may prefer to spend their time, in the words of an adult with DMD, ‘enjoying the little bit of time I have left’ (Gibson et al., 2007; cited in Gibson et al., 2014), rather than focusing on studying and gaining employment. Moreover, they argue that even those who have achieved what could be viewed as normalised ‘success’ through employment were still marginalised from their peers.

The aim of this article is to explore the ways in which the Takin’ Charge project has been helpful, if at all, in supporting young people with DMD and their parents to prepare for the future.

Method

Once ethical approval was granted from a relevant institution, 50 parents whose young people had graduated from Action Duchenne’s lottery-funded Transition to Adulthood project ‘Takin’ Charge’ were invited to take part in this study through letter and email, and 20 self-referred. All gave written consent for themselves to be interviewed by telephone.

The participants consisted of 16 mothers, five of whom lived in the Midlands, nine in the south-east and two in London, and four fathers, two from London, one from the Midlands and one from the south-east. Two of the mothers – one from the south-east, and one from the Midlands – had two sons with DMD who were part of the project. All of the interviews were recorded using telephone or iPad technology and transcribed. The transcripts were analysed using thematic analysis (Braun & Clarke, 2006). This involved identifying themes and patterns within the narratives through condensing the data into analysable units.

Issues regarding methodology and method

The deteriorative, life-limiting nature of DMD made it important to think carefully about the role of the researcher, and the impact of asking questions about the future to parents of young people with a life-limiting impairment, in particular thinking about the impact of sharing intimate and difficult thoughts with someone else. In a workshop about family adjustment in DMD, Eakes presented the ‘theory of chronic sorrow’, suggesting that for families affected by a chronic

impairment, grief can be cyclical. Parents of children with DMD can often experience grief at times when they are confronted with their child's diagnosis, for instance, at hospital appointments, or at times of major transitions such as the loss of ambulation – but these stressful times are interspersed with periods of happiness (Eakes et al., 1998; Poysky & Kinnett, 2009).

Similarly, in a qualitative study with 29 families whose child has a life-limiting impairment (including some with DMD) or who had lost a child, Stevens and colleagues discuss the difficulties associated with carrying out research with families who have to 'relive' difficult experiences while they remember diagnosis or share the difficulties of day-to-day struggles (Stevens et al., 2010). In his polemic 'Changing the social relations of research production?', Oliver (1992) warns against a model of research in which the researcher asks questions of the disabled person, leaving the latter feeling that all of his/her problems are caused by his/her own health problems, reinforcing feelings of isolation and personal inadequacy. The possible impact of the interviews could therefore not be underestimated, and regard was given to the consequences of searching for negative answers. In this study, a solution-focused style of questioning was used so that the interview itself could be an empowering experience.

Solution-focused questioning

Solution-focused questioning is a style of questioning that is loosely based on aspects of solution-focused brief therapy (SFBT), although it is important to stress that the researchers were not offering therapy. SFBT, developed by Steve de Shazer (1988), encourages people to find out 'what works' and do more of it, rather than focus on the barriers and problems (de Shazer & Dolan, 2007). It begins with the idea that individuals are the experts at coping with difficulties in their own lives, although there is no suggestion that there are no challenges (de Shazer, 1988). This is a similar approach to appreciative inquiry, a methodology that has been developed to support leaders in promoting change within organisations, focusing on what has worked well in the past, in order to explore the conditions that made excellence possible, rather than a deficit-based approach that concentrates exclusively on the barriers (Cooperider & Whitney, 2005).

The key tenets of questioning in the semi-structured interviews were, firstly, that language was future focused (for example, *'What are your best hopes?'*); secondly, that small steps can lead to big changes with questions such as *'What have you been pleased to notice as a consequence of this project?'* and *'What has it taken from you to make this happen?'*, working backwards rather than dwelling on the problem (for example, *'What do you want to see for your young*

person in the future?’ linked with ‘What have you been doing through the project to support this happening?’).

Positionality and participants

The two researchers who carried out the interviews had been involved in managing and supporting the project throughout its five years. Although this could be seen to limit the objectivity of the study, it was felt, as reported by Stevens et al. (2010), that building a relationship of trust with parents of children with life-limiting impairments is key to carrying out the research successfully, and as one of the researchers also had a son with DMD it enabled a climate of trust from the outset of the interviews. Both researchers worked closely to use similar wording in their initial questioning, and both met to discuss initial interviews in depth, and were reflexive in their interpretation of data and identification of themes in all interviews.

Findings

All parents reported that the Takin’ Charge project had been a positive experience for their sons and themselves, and when asked if they would recommend it to other parents they all said they would. In particular, four themes were identified that were viewed as key to the success of the project.

These were: hearing from adult role models within the DMD community; being able to share with and learn from families and young people with DMD; the need for resilience in ‘letting go’ as a parent; and finally, aspirations for a ‘normal’ life in the face of a life-limiting impairment.

The importance of role models in the DMD community

The most prevalent theme throughout all of the interviews was the impact of hearing and seeing adults living with DMD. As one mother reported: ‘he [her son] sees other people doing things and he thinks if they can do it why can’t I?’ This comment was repeated in most interviews, where parents reported the importance of hearing from someone with the same health and care challenges going to university or achieving employment or independent living. Many of the parents talked about the adults with DMD as ‘evidence’. As one commented:

‘You can have a middle aged lady talking to him as long as you like but it won’t be as effective as half an hour with a guy with Duchenne who has achieved something ... because it’s evidence – it’s there in front of you – he understands where you are coming from and he can give advice.’

Most parents were quite matter-of-fact about the use of respirators and wheelchairs but this had not always been the case. As one mother of a 14-year-old put it:

'Through seeing older men with Duchenne who have very limited movement or who have trachy [tracheostomy] tubes or PEG [percutaneous endoscopic gastrostomy] feeding tubes – all the sorts of things that if you just thought about them you might feel "oh I won't be able to do anything", but then actually he can see these people doing these things and not being held back by them and having a positive attitude. And I think that's helped him to look at those sort of interventions [trachy and PEGs] more objectively and see them as things that will help rather than see them as things to be afraid of.'

It was clear from all of the interviews that meeting and hearing from older role models was not without its challenges, and often demanded great emotional effort from families and boys. Several parents spoke about wanting to protect their young people from seeing older individuals with DMD as they felt this may upset them. One parent, whose 14-year-old son had had a diagnosis late (at the age of eight years), spoke about her son's reaction to seeing an older man with DMD speak at a Takin' Charge recruitment event:

'I think B's initial reaction to JC [older man with Duchenne] was shock because he had never seen anybody with all the equipment and the stuff and the chair and the breathing equipment. And I did think – I did look over to him – I remember looking in the meeting and thinking his eyes were welling up'

However, the parent went on to say that the initial shock gave rise to a lasting positive impact:

'he sort of mentioned him a number of times. And I know I have said I think he is the most amazing young man, one of the most impressive people I have met, and B in the end was really pleased to meet him and for him to be there – he made a pretty big impact I have to say.'

Importance of being part of a shared community

When asked what it was that brought them to the project, all families mentioned wanting to meet other families and in particular enabling their sons to meet other young men. Social communication issues are well established in DMD literature (Hinton et al., 2009; Hendriksen & Vles, 2008), and the majority of parents

spoke about their sons being 'shy' or being isolated, particularly as they had become non-ambulant.

Several reported that their sons had made new friends from the programme, and two families who live in the same area of the south-east spoke about how their sons were now hoping to live independently in shared accommodation when they are older. Others spoke about new friends, the chance to meet up and enjoy the different activities such as film making and karate, and continuing relationships through Skype.

One parent reported that although she had always fought for mainstream education, her son had never had the chance to meet other young people with similar difficulties as DMD is so rare. Another mother spoke about the impact on her son's mental health of meeting other young men:

'I think initially he was, as I say, he was very kind of withdrawn and just didn't see much point in anything. And then when he started doing the programme, there was a bit of a spark because they seemed to have some fun ... they started doing some projects on the computers sort of voicing their opinions a little bit.'

As a consequence of involvement in the project, the young person felt able to negotiate his situation at school, reporting to teachers that he was bullied and unhappy and eventually transferred schools. His parent reported:

'It was Takin' Charge I would say that definitely gave him a voice and realised he can actually say "you know what – this isn't good enough".'

It was not just the young people who benefited from meeting people within the DMD community. Parents appreciated the chance to talk about their own anxieties:

'when you meet people in the same predicament it's so much easier you don't have to keep talking about your problems but it's nice you can share your experiences.'

Others spoke about the importance of hearing how other families had succeeded at gaining certain resources or funding streams. As one mother put it:

'some people think that professionals have got all the ideas about how things should be. But when you speak to a parent – they are the people who really know – and I don't think you can beat personal experience'.

This was confirmed by a father who said:

'It's been really useful because I just believe that parents getting together – you see collectively we know a hell of a lot – but individually we have got massive gaps and sometimes you don't even know you've got a gap.'

However, the group was by no means homogeneous and, although valuing the opportunity to learn from other families in the Duchenne community, several spoke about their fears for their son being labelled as disabled or different and being denied the rights of other non-disabled young people. One mother explained:

'He has been brought up to not necessarily think of himself as disabled – or not to think of himself as less than anyone, because he has a right to be – to do what other people do'.

Another parent spoke about her hopes for her son at university:

'D doesn't want to end up in a disabled ghetto or with a load of geeky people cos you can just imagine that if you tell everyone able bodied you're in a wheelchair and there's another wheelchair you just get thrown in with them when the only thing you've got in common is you're disabled.'

Coping mechanisms and resilience

An important theme that is woven through most of the conversations is the need for parents to be emotionally resilient in the best interests of their young people, and having the strength to 'let go'. Several times different parents repeated the phrase *'It's not all doom and gloom'*, with one mother saying, *'you have to have a laugh, reign your emotions in as a parent.'* A father spoke about needing to *'grit your teeth.'*

'Letting go' of their young people was agreed to be a very difficult thing. One parent reported:

'it's one of the hardest things to do because you know – from the time they were diagnosed you just want to protect them ... then as they get older you realise you can't be selfish you have to let them go, you know you have to let them have a life.'

As many have pointed out, resilience is not just about personal qualities; social context and resources cannot be ignored (Runswick-Cole et al., 2014; Runswick-

Cole & Goodley, 2013; Ungar, 2005). Families welcomed the opportunity to learn from speakers on particular issues such as benefits and changes in special educational needs legislation, and learning from each other and sharing success stories. Many talked about the 'constant battle' of getting services and resources. One parent reported:

'because you've given me information I've used it as a weapon as I go to people to fight his corner so that's helped. It's made me more bolshy in myself. You know, before I might have thought no I better not say that, but now I do more because I've got a bit of background knowledge.'

It was clear from all of the interviews that having the ability to fight for services was very important. As another mother said, *'if someone turns you down that doesn't mean the answer's going to be no forever'*.

This ability to cope was linked to the importance of planning. A mother of two boys said: *'They can't just sit and let things plop into their laps because that's not always going to happen.'*

Nearly all parents reported on the importance of having a plan to ensure that their sons were able to get what they needed. Several commented on a workshop where they had taken part in a model person-centred planning session, and others spoke about the benefit of having their own person-centred planning session at home that was facilitated by a member of the Takin' Charge team. One mother described this as:

'the most amazing revelation to us because the plan we stuck on the wall here at home ... we all saw each other in 2 years' time and what route and path J needed to take'.

This, she reports, was useful because for the first time they were able to see all the different aspects of her son's life together in one place. This is particularly helpful in the case of a complex impairment like DMD that demands input from a variety of services in order for real outcomes to be achieved.

Increased aspirations for a 'normal' future

A recurring theme was the importance of getting what parents referred to as a 'normal life' that involved opportunities for employment and independent living. One parent spoke about the power of the Takin' Charge Employment Day in partnership with Treloars College:

'There are lots of opportunities . . . when we met up in Treloars that opened up my eyes because they had employers come along. I'm not an idiot, I know that being disabled is difficult but there are opportunities out there that I didn't realise.'

All participants mentioned the need to find out about support and often how difficult getting resources was for their sons to get the life they would like for them. Moreover, one mother said of the current statutory arrangements for transition:

'they just appoint somebody as a transitional worker – they don't really do anything – that's my personal experience. They didn't look at my son as somebody who has a future.'

One mother of two boys with DMD said that for her the most important impact of the project had been the raised aspirations of her sons:

'It's making them realise they can achieve . . . because I think a lot of them go in thinking right we are going to school then come out of school then what will we do? – maybe a bit of volunteering, you know very very low expectations.'

She reported how both her sons had begun to think seriously about careers since the project, and what skills and subjects they needed in order to do this.

One mother reported that through the programme her son had identified his ambition for employment: *'He wants to be a zoo-keeper... (laughs)... I don't think that's going to happen – it's all hands-on isn't it?'*, but she went on to explain that the project had supported her son to identify that he wanted to work with animals and to research other opportunities in this field that would be appropriate for both his physical and cognitive abilities, and that they were currently exploring roles in pet shops, garden centres and veterinary clinics.

Many parents contrasted how they felt now about supporting their sons into adulthood with how they had felt after diagnosis. One parent, whose son was about to start university to study journalism, said:

'When you first get the diagnosis you think – I've got be honest – I thought what's the point? What's the point of him going to school?'

Several parents talked about ‘dark days’ after diagnosis and one reported that before the project ‘he [her son] didn’t really look to the future at all or anything’. Another talked about ‘not being able to think past school’. One parent said:

‘it’s just like you do your grieving first and then you accept the condition – and even though it’s not a nice condition to accept – it’s part of normal life.’

As a mother of two boys with DMD said:

‘when we got diagnosed we just thought oh god our world’s ended. And it hasn’t – it’s just they’ve got to do it all in a wheelchair!’

Several of the mothers spoke about their desire to ‘be a mother again’, and enjoy spending ‘normal’ family time with their sons, one saying she was tired of being ‘the carer, advocate and cook’. Similarly, another said:

‘Some people they end up on anti-depressants and I think well that’s no good cos you just got to get on with it you know ... The only thing I’m feeling now is it would be nice to let go of S a little bit more with carers and be his mum cos I don’t want to be his carer anymore – but that’s what I am.’

Discussion

A key message from this research project is that parents of teenagers with DMD have valued a programme that has supported their young people to think about the future as any non-disabled young person would be supported to do. Notwithstanding, parents were clear that improved outcomes recommended in the new legislation, such as achieving employment, independent housing and social inclusion, would not be possible without detailed planning and resourcing and many spoke about the ongoing battles to achieve this.

Since the 1980s the disabled people’s movement in the UK has rejected a medical model of disability that views disabled people as victims of personal tragedy dependent on the expertise of professionals, and instead has viewed disability as a form of social oppression, the consequence of an ableist society that excludes and disadvantages people with impairments (Oliver, 1983). According to the social model, it is not a person’s impairment that disables them, but society itself which denies disabled people access to opportunities open to the non-disabled

population. The social model has been key in the fight for improved economic, social and political rights for disabled people, but it has been suggested that it is inadequate in explaining all the challenges that people with chronic impairments face, and it is important to acknowledge ‘impairment effects’ that no level of legislation or accessibility can remove (Thomas, 1999; Crow, 1992; Shakespeare & Watson, 2001). In the case of DMD, these effects can be seen in muscle degeneration that leads to the loss of ambulation, weakness in heart and breathing muscles, and ultimately early death, as well as raised risk of cognitive differences that can affect academic achievement. Linked to this is the raised risk of internalisation and adjustment difficulties that young people with DMD can experience as they lose the ability to walk, and the increased levels of stress associated with parents of children with DMD in comparison to those with other chronic impairments (Hendriksen et al., 2009; Holroyd & Guthrie, 1986; Nereo et al., 2003).

Similarly, some writers have argued that in addition to social and economic challenges, disabled people face attitudinal challenges in what Thomas (1999) refers to as ‘barriers to being’, and others have claimed that this oppression can become internalised, which ultimately changes and reduces aspirations (Reeve, 2004; Campbell, 2008). This can be explained by the construction of ableism or normalcy in society that operates both ‘out there’ and ‘in here’, not only perpetuating oppressive practices but causing disabled children to lack confidence, believing that their marginalisation is caused by their own impairments (Hehir, 2002; Hodge & Runswick-Cole, 2013).

In a study on disabled children’s views of disability, Connors and Stalker (2007) found that the children they interviewed tended to highlight the similarities they shared with their non-disabled peers rather than the differences. The authors suggest this could be due to disabled children lacking both role models in the disabled community and the language with which to discuss difference. Similarly, from interviews with adults with DMD in Canada, Gibson and colleagues question whether men with DMD should refer to their success in terms of employment and residential independence, in the same way that other typical non-disabled adults might do. They write: ‘There was no other narrative map of DMD to draw from in which they may recognize themselves in a positive way’ (Gibson et al., 2013). Others have also criticised this normalised focus on work and independence as being the markers of successful transitions (Priestley, 2003). Perhaps for young people who have less time and energy due to the nature of their deteriorative impairment, there should be a focus on other things?

Following this line of argument, it could perhaps be argued that the emphasis on issues such as employment and housing in the Takin' Charge project served to reinforce these normalised expectations of adulthood, that are not appropriate for those living with a deteriorating and physical impairment such as DMD.

On the other hand, enabling parents and young people to hear from adults with complex physical and medical needs about the challenges of getting a job or a flat, or embarking on a relationship, could be seen as a form of resistance that helps expose what Campbell (2009) describes as the barriers systemic in an ableist society. Through the project, adults with DMD were able to share their experiences and initiate discussion about concerns such as the absence of Government assistance for work experience, or lack of access to leisure or transport facilities. Furthermore, through supporting their young people to experience employment, independent living and relationships, parents may well have perceived themselves as disrupting the roles 'prescribed' for them by society. It was clear from these interviews that parents challenged what they saw as lack of aspirations for young people with DMD, and were determined to support them to be, as one mother said, *'just doing it all in a wheelchair'*.

It was, however, also apparent that parents had not always been so accepting of living with DMD. All participants reported bleak emotions at diagnosis which had transformed into a different outlook as their children grew older. As Landsman (2005) has noted, initially when their child is diagnosed mothers of disabled children tend to adopt a medical view of disability as they focus their energy on the search for a cure and treatments, whereas as their child grows older they come to terms with the situation, begin to value difference and fight for services, adapting to a more social model. This suggests that those professionals who are responsible for giving the diagnosis of DMD, and those who are supporting families regularly, need to be aware of the improved life expectations for young people with DMD, in order to share higher aspirations for their futures.

Interaction with the DMD community was shown to be important for both young people and parents during transition, with parents appreciating both the emotional support and practical information they learned from each other and from workshops. As Curran and Runswick-Cole (2014) argue, 'Enabling peer support is crucial to building resourceful families'. This is particularly true in the case of a complex and rare genetic impairment such as DMD where information between hospitals can vary despite the internationally agreed standards of care (Bushby et al., 2010), and where schools, social workers and GPs have often had very limited experience of meeting young people with DMD. However, the Takin'

Charge group was by no means uniform, and diversity in outlook, beliefs, support systems and resources are reflective of the DMD community, as well as the disabled community in general (Meekosha & Shuttleworth, 2013). This highlights the need for tailored and personalised support whereby the young person identifies his aspirations and needs, and whereby provision follows the young person rather than dictates his future. Notwithstanding, all young people with DMD do face a similar physical prognosis, and the group reported that it was helpful to share possibilities and experiences as well as to be with other people who fully understood the emotional challenges they were facing. A research focus over the past decade on the resilience and strengths of families of disabled children has been criticised by many who feel that concentrating on the personal growth, 'transformational coping' and emergence of the 'super parent' has lost sight of any political and social context. This can lead to the marginalisation of families who are struggling for resources and support (Knight, 2013; Muir & Strnadova, 2014) and can place the responsibility of resilience on the individual family rather than seeing it as a civic responsibility (Goodley, 2007).

Furthermore, several authors have pointed out that resilience is not just the ability to 'bounce back' from a difficult situation, but is something that is dependent on a range of available resources that can be material, legal, attitudinal and social as well as emotional (Ungar, 2011; Runswick-Cole et al., 2014). This is particularly true when a lack of resilience might be used for blame in a climate of austerity, and when we know that parents of young people with disabled children generally have a higher risk of stress, family breakdown and social isolation (Runswick-Cole et al., 2014; Muir & Strnadova, 2014). In addition, as some have noted, the neo-liberal agenda that is offering more choice and control for disabled people, through the use of direct payments and personal budgets, is simultaneously dismantling the welfare state (Morris, 2011; Mladenov, 2015), which could ultimately lead to less support for disabled young people and lower wages for those working in care. Indeed, in these interviews parents still refer to ongoing struggles with service providers and the importance of being informed and having a detailed plan for the future, despite the ethos of better outcomes and higher aspirations embedded in the new legislation.

Limitations and strengths of this study

Families self-referred to the Takin' Charge project, and out of the 50 families who were contacted to be included in the evaluation, only 20 responded. This suggests that the families interviewed may not be representative of families with DMD as a whole, and therefore this makes it difficult to generalise about parent perceptions of the project, and of transition generally. The strengths and

uniqueness of this project lie in it being the first evaluation with parents of an intervention for young people with DMD who are preparing for adulthood. Indeed, until quite recently they simply did not live to adulthood. In addition, the young people and adults from the steering committee have been interviewed about their perceptions of Takin' Charge, and it is hoped that these findings will be published in a parallel paper. We know that there are now many more young people alive with a range of life-limiting impairments than there would have been 20 years ago, and so this study has a wider relevance than just DMD (Fraser et al., 2012). In addition, the project has been running at a uniquely important time when new 'aspirational' legislation has been introduced for young people with special educational needs and disability. Moreover, the methodology used has supported participants to focus on what works well in their lives, thus fulfilling an empowering as well as an investigative role.

Conclusion and recommendations

Service providers such as local authority transition teams and schools should give mind to the novel power of adult role models for impairments such as DMD, which are life-limiting and complex, but now have much improved prognoses. In order to improve outcomes and aspirations as outlined in the Children and Families Act 2014, families, young people and professionals need to be given opportunities to hear from adults with DMD and other families to understand what 'aspirational' can mean, as often having a life-limiting impairment can severely limit one's understanding of what is possible. With the introduction of personal budgets, this could isolate individuals further if they are not aware of how to spend their money, and on what.

At diagnosis parents had not been given information about the improved prognosis for DMD, or if they had, it had not been consistently given. Therefore all families who mentioned diagnosis had traumatic memories which had led to low expectations. This indicates a training issue for doctors and other health, education and social care professionals at diagnosis and in ongoing care and support. It is essential that those working with young people with DMD have an expectation that they will live into adulthood and therefore support them to plan accordingly.

There is a role for Transition to Adulthood projects that inform parents and disabled young people about opportunities that are available, such as how to use personal budgets, and that support skill development. Using solution-focused approaches can be helpful to elicit what works, and to identify best hopes for the future. In addition, the expertise of families in DMD should be acknowledged by professionals.

Good person-centred planning that enables young people and their families to identify life outcomes, and the necessary resources to reach them, is key to ensuring people with complex and life-limiting impairments achieve their aspirations. This involves thinking about what needs to be in place today so that future achievements associated with a 'normal' life, such as employment and independent living, are a real possibility. It is also essential that planning is personalised, as young people with DMD, although facing a shared physical prognosis, may have diverse aspirations and abilities.

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